

ORAL HISTORY RECORDING TRANSCRIPT

'Fighting for our Rights' project

Surname	Macfarlane
Given name	Ann
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Place of birth	Thorpe St Andrew, Norfolk
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IA: This is an oral interview with Ann Macfarlane by Ijeoma Aniyeloye on Thursday 27 April 2017. The interview is taking place at Ann's home in Surbiton as part of Kingston Centre for Independent Living's 'Fighting for our Rights' project. Hello Ann.

AM: Hello.

IA: Could you please state your full name?

AM: My full name is Ann Macfarlane.

IA: What is your date of birth?

AM: Oh, is that important? [REMOVED] 1939, how about that?

IA: Where were you born?

AM: I was born in a little village called Thorpe St Andrew in Norwich, Norfolk.

IA: Did you grow up there?

AM: Not really, no. I lived there till I was about three, almost four. Then I was in hospital and, you know, you don't really grow very much in hospital [laughs]. And yeah, then I was just moved around and I went home for about... I think I had a period at home of around seven weeks when I was about seven, and then I went on to go back to hospital. Then I went to a long stay hospital called Melton Lodge in a place called Great Yarmouth on the east coast of Norfolk, about 22 miles from this little village where I lived. And the place no longer exists, it was knocked down some time ago. It was first of all changed into a naval block of buildings and then it went on to be demolished for something else. Not a happy memory.

IA: What were your parents' names?

AM: My parents' names, they were Frances Emily and David Alexander.

IA: What were their professions?

AM: Well my mother was a housewife, a very hard working housewife, and my father started off as a--, like a travelling representative really, and then went on to be--, eventually, with his years of knowledge, went on to become a director of about 80 shops that sold toys and nursery furniture.

IA: Would you mind explaining the nature of your disability?

AM: Well, the nature of it is that I've been left a wheelchair user for almost--, after I was able to get out of bed, I've been a wheelchair user for... years, I suppose, since about the age of 11, something like that, until the present day. Which means that my mobility is very, very limited now, you know, to a few steps with crutches. And yes, I've got very little movement in my upper body but apart from that other things still work really [laughs].

IA: Where did you go to school?

AM: Ah, well I call it the University of Life. But in essence I was a very fortunate less-than-four year old. I got into school at four--, I was four years and nine months, and that was very, very important because it was at five years and three months that I became hospitalised. So I had six months at school, and those were the days which really focussed on reading, writing and arithmetic as it was called then. And that really stood me in fantastic stead for what was to come, because there was no education in hospitals. I could tell you every single thing about operations, dressings, everything to do with nursing and medical things like keeping the corners of the bed absolutely pristine and making sure the wheels were straight and there was not a speck of dust on them, and the sheets pinned you to the bed. And other than that, so I was very immobile, and my saving grace was the ward clock. The ward clock, which I could see most of the time, helped me to play lots of ridiculous games, all sorts of games with myself because there wasn't anybody else to play with other than all these other children who were in the same predicament as myself. So it was really very, very useful.

IA: How old were you when you left the hospital? I'm talking about the long stay now.

AM: Oh, I was about 14 I think. And then I came home, but not to Norwich any more because in the meantime my parents had moved to New Malden, which is in the borough here, and I went to this school called Bedlesford which is a school for disabled children, where I learned nothing. Because I was the oldest person in a class which started at the age of nine to 16. So it meant that with one teacher and that terrific age range and with children with all sorts of abilities, it meant that I did a lot of the teaching, cleared up after a headmistress who had the most awful temper because I think she was a very sick woman, but you know, when you're 15 you don't really understand all the ins and outs of that, but I think she was a very sick woman. But she had an almighty temper and she abused the little tots absolutely terribly, to the extent where if they didn't get something right she'd grab them by the blazer until all the buttons fell off and they wet their pants and then, you know, I had to sew all the buttons on before they went home otherwise the parents would be complaining. And it happened regularly, always in assembly, you know, when the children came together. So it wasn't easy. I think I learned to ice a cake actually, now I come to think of it [laughs]. I think I came to ice a cake, something terribly, terribly important. At least you use it maybe once a year or never again. So yes, so it wasn't good, and when I left they wrote--, I left school when I was 16. I should have stayed on but my parents were written to and said that I'd reached 16 so I was no longer entitled to any more education. So I was a bit restricted education-wise, because in hospital the only chance I got to have any education that I remember was when I was nine at this place in Yarmouth, and when the teacher saw me, bearing in mind I was nine when I went there, and the teacher said to me, "Now I want you to read this book," and she gave me a book of nursery rhymes and I said, "I'm not reading that," I said, "I can read far more intelligent things than nursery rhymes," because of course I'd done all this

learning for six months, I'd played all these games with myself, you know, so my vocabulary was quite good. Oh, I was just--, so after that she took umbrage and that was it, I was out of favour. So it was all pretty hopeless. Yeah, so education wasn't a strong point in my life.

IA: When you left school did you get a job?

AM: What happened was that when I left school, almost immediately after I left school I went back into hospital for some major operations, and I finished those when I was 18 and they sent me to a rehabilitation centre where I stayed for a year and did nothing. Oh I did, I made cane baskets, very useful. And then I went home. So at 18 I was pretty well uneducated as such, had no real skills. In hospital, in the last hospital I was in, they had given me a typewriter. I mean there were no computers in those days. So they gave me a little typewriter, and there was a gentleman that used to come round and try and help people. But you know, when you're lying on your back and all of that it's very hard to do some of those things. And yeah, so when I went home my father said, "Right, well what are you going to do? You need to work." In the end I got sent to a college in Leatherhead, it was one of these colleges for disabled people, and I lasted there ten days. It was such a dreadful situation. I went on a course for typewriting and shorthand, because in those days any disabled person either become one of three things, they either became a secretary or a typist, they became a lift attendant, because in those days they were not electronic like now, digitally arranged, they were just the old push and pull. And in those days of course at the end of the war any ex-serviceman or particularly men who came back from the war, that was what the government allocated them as a job, lift attendant, when they'd fought for our country. And the other job was telephonist, particularly for people who were blind. So those were the three main jobs. So I obviously felt that I had to train to be a secretary, so I went to this college where they started off by being really pleased to have me. But of course for someone like me there was absolutely no help, it was awful. So you know, I used to start getting up at five o'clock in the morning to try and get to the lessons at 8:15. You had to get your own breakfast, I mean I could never have breakfast, I was never ready to have breakfast. And the sister did the least possible, because they had a sister that was supposed to support people that needed help. And she would only come at the very last minute. And in the lunch break when I needed assistance with the toilet, I could stand, because in those days I could stand for a long time, and I used to stand for half the lunch break and she'd never turn up. So what happened was I slipped and broke my arm and she never told anybody, so I was stuck in bed until my parents came to pick me up for the weekend, and of course when they saw what had gone on they were furious, well my father particularly was absolutely furious, as you would expect really, or hoped. And so they sent me home in an ambulance and I said to my father I am not going back, there's no point, I can't learn, I can't concentrate for a start, because not only that, they wouldn't let you sit in your wheelchair, you had to sit on these blessed swivel seats, and all the time I was sort of facing the back of the class most of the lesson [laughs], it was ridiculous. But that was how it was in those days, you know, there was so much that needed attention and understanding, and of course they didn't. They had only the most able of students, a bit like they still do now in many situations. Yeah, so my education--, and of course, so what happened was, going on to find a job, my father sort of said then well you're at home, what are you going to do? And I said well I'm not qualified to do anything until I take some qualification or at least some lessons in something. So I decided that I would engage, if I could find one, a private tutor. Because I needed transport to get out, I mean we did have a car but my father needed that for work. So it was incredible really, I put an advert in the local schools, you know, like the--, yeah the schools really, and adult education, and oh within a couple of days I got a really good response saying yes I'd like to come and teach you. And this woman came, I just remember her so vividly. She was very, very short [laughs], she used to come with at least two coats, three hats, four scarves, and announced every time she came in the room, "I've got a bit of cystitis dear, today," [laughs] she was always saying--, she was hilarious. But she was a first rate teacher, she really made me stick at it. That was what I needed, I needed somebody who believed first of all that I could do something, and secondly that she would ensure that I did do it and got it done. So that was all done. She stayed with me for nearly four years, because it took a long time, because I was in and out of hospital so many times so I had to pick up again every time I came out. But in the end I had enough qualifications to teach other people. So I decided to set up in private practice. I wanted to train as an external teacher, but the Royal Academy of Arts at that time wouldn't let me take

the exams, the reason being I couldn't write on a blackboard. I mean they couldn't do that now, but in those days that's how it was. Fascinating stuff. But anyway, I had a very, very good practice for about seven years. And in between teaching students my father got me several jobs at home, you know, just doing this piece work sort of work, ranging from curling dolls' wigs to--, the main one was invoicing, for his firm, not for him but for his firm. I used to have to work out all the invoices, which was sometimes for thousands of pounds. I didn't have anything, no calculator, nothing, and looked at all the tax and all of those things. And you know, I'm not very good at maths but I did manage to do that, I held that job for about ten years, in between everything else I was doing. And that could sometimes be six, seven, eight hours a day. So it was pretty difficult in between trying to teach and doing everything else. But you know, in a way that was so good because I earned some money. Oh and in between that I used to type doctors' theses, their medical theses, especially for the gynae and obstetric doctors. So they used to come to the house and bring all their manuscripts, awful writing, all the manuscripts that I had to plough through. But I did that for quite a long time. Yes, so you know, I managed somehow or another to earn a living, well what I'd call a fair living. Yes, but all the time I did all of that, all I wanted to do was to go out to work, that was my goal. Because I had no social life, I had nothing. No friends. So after writing hundreds of letters with nobody either responding or saying well you wouldn't be able to manage here, whatever the excuses were, in the end I decided to write to Kingston Hospital and say look, I'd like to do medical secretarial work. I'd studied the medical dictionary from the front cover to the back, so I could spell. And in the end they said yes you can come and work for us, we'll find you a job, we haven't got one now but in about 18 months' time we'll have a job. Talk about equality. And anyway, 18 months went by, never heard a word. I rang them up and said look, come on, how are you doing with the job. And they said well we're ever so sorry to tell you but unfortunately the job is on a mezzanine floor level and we haven't got a lift. So I said oh thanks very much. I said when are you going to find me something suitable, because I haven't even got any experience yet outside, I must get experience. Well eventually, not too long after, they did ring me up and say would I come and be secretary to one of the consultants and his team, because the person had gone on holiday. So I went there for a fortnight, I was absolutely over the moon, I did the work, the consultant liked me, and on the last day of the fortnight the HR person came and said right, well time's up, very nice of you to help us, we're very pleased to have seen you and met you, if we've got anything else, you know, eventually we'll let you know. I was really upset because I thought oh surely they could find me some other holiday vacancy. But no, they lied. And what happened was that about an hour later he came back and he said do you want this job, and I said yeah I do want it, you know I want it, and he said well you can have it. Because the woman had not gone on holiday, she had left, and they didn't tell me. I mean in any other circumstances I would have said stick your job, but you know, I was so desperate to get out and have something to do. I was allocated one of these three wheeler vehicles that the ministry--, they don't make them any more, but they used to give to people if they qualified. So I used to drive myself to the hospital and back every day but it was a nightmare. I had to keep one wheelchair there to get into because there was no way I could set up an electric--, you know, because in those days the wheelchairs weren't like they are now, the cars weren't like they can be now. So it was really a struggle. And then after I'd been there for about two years or less I had to leave home because my parents were really--, it was too much and, like a lot of parents, getting older and my mother was really struggling, it just wasn't fair on her. And basically I jolly well wanted to leave home, you know, because I was 29. But you know, where do I find an accessible place? Nowhere. And in the end, after searching the country, I went to live in a place called The British Home and Hospital for Incurables. So that did me a nice lot of good. No, actually it did me a lot of good. Whatever was awful about the place, for me it gave me a springboard to get back into Kingston, because I decided that--, I made them agree that if I went to live there I would keep my job. And of course at that time no disabled person ever lived in a residential home and went to work, I mean that was just never even thought about really. So I mean the doctor and the sister, matron or whatever she was, they were awful to me. Particularly the doctor. He called me fat, lazy, all sorts. He didn't even know me, but that was my first interview. And the sister carried that on. But in the end I said to her look, I said if you carry on like this I'm going, I'm not staying here, I'm not going to be spoken to as you're speaking to me. After that we became the best of friends, that was great, she was really okay then. But you know, all battle-battle, all the time. But the house governor, in those days you know they had--, army people often looked after these places. Anyway, the house governor was a very decent man and I thought right, of all the people I need to be on

the best terms with him. So I mean the rules were so strict, I mean I left the home before breakfast because I had to get out early to get to work, and I got home after they'd finished serving the evening meal. And of course they often forgot to leave me anything to eat, it was dreadful. And one day I was so fed up I went to the fridge, because they used to leave in the fridge a little box of cheese cubes and a pint of milk or something like that, so I went there, I found these cheese cubes and I also found a couple of lettuce leaves and about half a tomato. So I stuck them on a plate and then I drove along to his office with a big notice on it saying rest in peace. Well, he came out of that office like a flash in the morning and said what is all this about. I said well, I'm so hungry I said, look at all the weight--, I had lost of lot of weight. I said I'm starving, and I said at work I can only get to the WBS canteen or whatever it was called, and I said that's it, and I don't get anything in the morning, I said I'm paying a good whack of my salary, I mean it was a huge whack, I was left with about £6 a month so I couldn't really buy anything much, and I said this isn't good enough. I said if you went home to your wife and thought you were going to get a good meal and you found that you got a couple of cheese cubes, what would you think? I said it doesn't take much intelligence to come up with your answers. Anyway, he then agreed that--, he wouldn't really agree to give me any of my fee back, but in the end after a lot of arm twisting I managed to get a kettle in my room, and I managed also, much to his--, I don't quite know what, but he was terribly worried, I got one of these--, I don't know if you've seen them, but they're like a frying pan but they've got a lid and you can cook anything in them. So I got one of these, which he insisted had to be in another room somewhere up the corridor, but you know I said I can't, I'm worn out when I get in, I don't want to be trooping up and down corridors, I want to at least do something. So that worked. And then in the meanwhile, this is where Kingston Centre of Independent Living comes in, we've got to that bit now. I'm sure you've got other questions you'd like to ask me, haven't you? I don't want to go off track for you, but you know, you've asked me these questions and they're very long answers really.

IA: I was going to ask, you know, from that job to joining the Kingston Centre for the Handicapped, what happened between--,

AM: Yeah, that was what it was called, yes, it was called Kingston Association for the Handicapped. Well, it was very interesting. I joined about nine months after its inception by an architect called Wycliffe Noble. By that time he was quite a world renowned architect because he focussed on access for disabled people. So he was the right man, in that time, for the job. He gathered one or two disabled people together, and another disabled person asked me if I would come on the board and I said yes I'd give it a whirl. But in those days it was all what I call pretty knitted cardigans and pearls, it was the ladies who do tea, you know, what sort of thing in the afternoons. I'm being very critical, but it was like that, that's how it really was, and still is in some parts today. But anyway, they were really dedicated to getting the organisation going and trying to make a difference. So I joined and I very quickly became the honorary secretary. And I worked at that, because then I went to Streatham where I was in this home, and I still kept that job on from there, it was jolly hard work because you know, not being in the centre of things. But I muddled along. And when I came back to the borough, which was about just under two years I got back, and it was because of one of the councillors on the board who helped me get some housing, because that was the stumbling block, because then I had to tell the home I was leaving. Oh dear, I psyched myself up, it was awful because I mean it was just unheard of, people didn't leave homes, only in a coffin you know, so it was very tricky. Anyway, when I got back that night, I mean I decided, I'd written to the house governor and said look I need to speak with you, can we arrange a meeting. So he arranged a meeting, and I'm sure he knew what I was going to say anyway, because I was shown into the boardroom, I was given sherry, I was well pampered, and he said yes you can leave, but he said I am concerned, because he knew that there wasn't any social care, community care, there was nothing really, only nurses who worked limited hours and only did certain jobs. So he said look, because I feel a bit anxious of you going, he said, I'm sure you'll make a success of it but just in case I'll keep your room for ten weeks, I don't know why he chose ten weeks, but anyway ten weeks was quite a long time for any nursing home or hospital to keep a bed for somebody. So I left with trepidation really because I'd never had to fend for myself. But I'll tell you this funny story, when I first got to this home, I was three floors up, right, looking out onto a pretty main road, and my boss had given me this kettle as a moving present, and when I made my first cup of coffee, when I

was allowed to use the thing, I got this cup of coffee and I sat at the window, and all I wanted to do was shout down to the people passing by, "Look! I've made my first cup of coffee and I'm 29 years old!" and I thought oh no, I'd better not do that or they might think there's something really wrong with me [laughs]. But yeah, I was so thrilled to feel that I was becoming a bit more independent, and I did become quite a lot more independent, and in the end apart from that, for myself, I became the resident social worker because everybody came to me with this problem and that problem. And some of them were really difficult problems, and so I did learn a lot, although at the time I was annoyed often because I was so tired. I mean I was so ill at the end that they had to admit me to hospital for three weeks because I'd lost so much weight and I was in such a terrible condition. But you know, I survived all that and couldn't wait to get out. So yes, so that was really when I came into the organisation. And when I came back to Kingston, by that time Wycliffe Noble had said we've got to try and find an office, we've got to have a place where you can work from, because I was surrounded by files at home and I'd got no one to help me, and the queries were all so big and took so long to solve. So I went to the church that I belonged to, because I'd belonged to this church before-- , well not before I left home, but I'd belonged to another similar church, and I went to the minister and I said look, is there any chance for a very, very small rent I could rent an office here, because it's a big place with loads of rooms. And he said well you can have my... what do you call it? Vestry, that's what they call it, you can have my vestry, because he said I don't use it very much. So I turned it into an office for a real peppercorn rent. We only got £100, that was what the fee was in the beginning, not the fee, the grant was £100, and we had that for several years, nothing moved even though Wycliffe stormed on all the doors in the council. Yes, so I progressed, I was chair for a long, long time of the organisation. It changed its name. The most wonderful, wonderful day was when we had a coup. My friends and I decided that we were sick to death of the chair and all the other ladies with twin sets and pearls, and we thought we've got to oust them out really because we needed to have our own agenda. So we waited until the AGM and then when the nominations came up, because it was done beforehand but even so nothing was decided, so we'd put all our names forward for all the key posts. And there was an absolute storm. Of course people were terribly upset, but then you know we were very sorry, but something so drastic had to be done because the organisation was still holding daffodil balls, you know, I mean it just didn't work for us [laughs]. They were very heady days, they were so exciting, because not only was all this stuff going on at local level, it was also at national level. You know, I was in the founder group for Dial-a-Ride, for Crossroad in London, because it was a time when Ken Livingstone threw loads of money at minority groups. So it was very, very exciting. And I met with loads of likeminded people that I'd never met before and got really into the whole thing, and loved it. Most of the time. The things I didn't like and didn't engage with terribly well were the marches and things through the streets. I was very frightened to be honest because of, you know, the police were-- , instead of being lovely policemen who started to really help people across the road and done all those sorts of nice things for these poor pathetic grey things, they then got really stroppy with us, and you know one of these marches resulted in holding the whole of Westminster Bridge took over, so nothing could move on Westminster Bridge in London. I mean it was so exciting. But the people, I mean disabled people were arrested, but of course the police couldn't get them into their vans because they weren't accessible [laughs]. So it was hilarious really at the same time, but those disabled people were very brave. They chained themselves to trains in the stations and wouldn't let them move, and the passengers used to be furious, you can imagine, "How dare you hold us up for work!", well we haven't been able to get to work so don't start moaning at us, you know! [laughs] So they were very heady days. But of course all that has gone more or less now, because over the years we worked so hard to get access on every level, I don't mean just steps and things like that, I mean signage, colour coding, all the things that are important to disabled people, you know, irrespective of impairment. You know, so for people with sensory impairments trying to get traffic lights or the crossings so that they beep, all these sorts of things we did. So of course younger disabled people have never known that era, so they take it for granted, and isn't that a great thing, you know, I'm delighted they can. But of course what they don't realise is that things are all falling back, they're all going, and I mean all. There's so many slippages now that we do need a lot of work doing. And that is why KCIL is trying to find time, people, money with enough knowledge and qualifications to do access audits, try and work with the council and others to make sure things are done correctly. So you know, Patricia, one of my great friends Patricia Page and I, we did the whole of the disability policy for Kingston Hospital on access, and we set up a committee for them and worked for about ten years on that

alone. I mean not alone, with everything else going on, but you know what I mean, it was a real focus at that time. So yes, so I've seen some very, very interesting times. And that's one of the things that age, you know, where it's a real plus because you see the changes in society whether they're good or bad. You know, for example one of the big things we're seeing in Kingston at this moment is the whole social care scene where all the teams are changing, all the social workers come and go, people at risk can't get a decent social worker to make sure they're safe and all of that. Because they don't know who the social workers were that dealt with it before, or they only know their name on a piece of paper. And I mean I'm dealing with an individual situation at the moment that is really worrying me, I've a very, very longstanding friend in a home locally and she is being abused day in and day out, and trying to--, I won't go into the situation because it's not for the tape or for this interview, but these are the sorts of things that if I can, and I see it's absolutely imperative that I try and do something and not interfere, then I will do it. And in this situation, this has been going on for years and it's just taken so long and it's still--, you know, oh I won't tell you, but it's been really awful because I just feel for this person, I just feel her life is just not--, how she's kept going for all these years and stayed sane I'll never know. So you know, but while the association can't deal with all these individual situations, well they can occasionally obviously, particularly those on personal budgets and those sorts of things, they can't deal with this wider picture, we just don't have the staff and the time. We have to deal with policy and practice, which is fine, you know, because that definitely needs sorting out. So yes, so I've come through, I'm now patron of the organisation. I don't do anything for that, it's just a six letter word. I've been pleading with the Chair for years to give me a role, I've told them what the role could be, but sadly he's never asked me to do anything. And I think that's because he feels very nervous that I'm a troublemaker. If only he knew. If only he really understood me, he'd know that is not my way to work. I can be really, really firm but I don't undermine people or criticise in such a way because it doesn't work, you've got to work with people to get things done. But it's very sad that he won't use me intelligently over anything. You know, we could have lots of opportunities in this borough, for example to give talks. No. Don't ask me. You know, and it's such a shame, that's one thing I could do. I became eventually, you asked me what did I do, what was the next job I did, well since 1988 I've been a disability quality consultant and mainly spent all those years training social and healthcare staff. A bit in the private sector, but I didn't like working in the private sector very much. Health and social care were really my focus, and I've done--, so now when I go out all over the place everyone can recognise--, well not everyone, but people in the field say, "Oh Ann, I haven't seen you for ten years," "Oh you're still here?" [laughs] Talk about tact, you know! But anyway, it's all good stuff. But now it's really nice to have people recognise you sometimes and catch up on the intervening years that have gone between, and those sorts of things. Yes, so that's been my work, and I still do some of that work outside. I work for the Care Quality Commission now, so I'm a lay inspector for going with their inspectors into homes and GP surgeries and dentists, all those places, to inspect them. But mainly my role of course is the best role because I can go and talk to anybody I like, so I can unearth any little worms that might be crawling around in the woodwork, with any luck. But you know, I'm looking for good practice as well, of course I am, and you know there are homes where they try very hard but life is a bit tough for all sorts of reasons. So you've got to see it from--, you know, any job like that, you've got to see it from both sides. Our social care workers in the field are very poorly paid, you know, the care workers, dreadfully poorly paid. And not given the credence which is due to them, because they're often the ones that are dealing with such difficult problems day to day. And for the pay they get, I mean my PAs are paid appallingly, and you know, when I think most of them have been with me for ten years or more, many more years, and they're still getting pay that was allocated for--, well years ago, but for the last four or five years they've not had a pay rise and that's not really good enough. But anyway, that's another story. So yeah, my friend and I, we set up personal budgets in this borough. We wrote the policy, got an appointment with the director of adult social care, knocked on the door and said look this is what we want, and this is what all disabled--, well most disabled people would like if they understood how it could work. And she agreed, and she took the policy to council and it was passed the very first time, so we were mega pleased. But yeah, so there's been some highs and some lows, as you can tell.

IA: I'll take you back a little bit. In those days did you partner with any other groups?

AM: Yes. Yes I did. One of those groups was called the Rangers, you know, like the Girl Guides. Years and years ago. And I became a Ranger for a short while, but all the work mainly was done through the post, so you got a book with like what you had to learn and sort of problems you had to solve, and then you passed it on to the next person. So it was still an isolating sort of experience. But about once every month or two months we were able to meet up, and one of the people that was in this group I still meet up with twice a year today, we still keep the contact, and that's really lovely. Yes, so that was one group. This wasn't exactly--, oh I tell you where I did learn something. Years ago in the Rangers, when I sort of was getting to the end of--, well I think I was out of the Rangers by then, but somebody that I knew was arranging a holiday for disabled people in Switzerland, and somebody had dropped out right at the very last minute and they rang me and said any chance you could fill the space, and I said that'd be great because I'd never travelled anywhere outside my front door really, other than work. But of course I hadn't realised that this group would be about 60 disabled people and about 60, 70, 80 helpers. Oh dear, we flew in a plane, it took three or four hours to load the plane with all these different people with different abilities, trying to get them packed in. I mean the airline had never seen anything like it I don't think before. And we got to Switzerland, and we were put in two hotels fairly close to each other, but after we'd been there a day we had a big complaint from the other guests saying that they would not tolerate us eating in the dining room with them and we had to eat in the garden. Oh yes, it all happened, and we said no we're not having breakfast in the garden. So in the end the hotel allocated us a spare bedroom and we all had to try and squash into there and eat breakfast. Oh yes, so I vowed--, and every time we went anywhere it took hours to get loaded up in a coach and oh it was so--, you know, I loved the--, I mean the scenery was absolutely out of this world as you can imagine. If you've been there, well yes it's wonderful. I've never been since, but I would never go in a group like that. I've never been since and I never would even begin to entertain it. So it was something I really learned. But you know, it wasn't the disabled people I was with particularly, it was the big number and the fact that it took so long to do anything. You know, can you imagine trying to get up in a lift in the hotel one at a time? Oh [laughs]. Anyway, and the reason I was able to go was an aunt of mine who died very young, in those days she left me this princely sum, and it was quite a lot then, of £200, which made it--, you know, I was able to go, which was great. And with money I'd saved of course. So that was a good experience in terms of thinking gosh I should be able to do much more with my life. So having now travelled the world I feel very pleased that I had that experience, otherwise I'd never have known what I could do really, or what was possible even with, you know, although I needed a lot of help, that I could still do it.

IA: Talking about money, you mentioned you got a grant of £100 in those early?

AM: Yes--,

IA: So was it enough, and how did you get extra funding?

AM: No, this was for KCIL, this was for KCIL.

IA: Yes.

AM: Well, we had to sit in the street and rattle a tin. Oh, that's another funny story. One of my friends, not here but in London, was outside rattling a tin, because we all had to do it across--, you know, all our organisations were poor. And there she was with her tin--, oh no, it wasn't with her tin, there she was sitting drinking a can of Coke outside a shop door, and this woman came along and put her money in it! [laughs]. But the begging bowl is my worst nightmare, you know, and KCIL have found that very hard because I said, you know, if you're going to get us collecting in the street I really can't do it, I just can't. I mean it's quite hard work for me anyway now, I can't hold the boxes. But even if I could I don't want to do it, because that really is going back to the basis of charity. And that's where most of us have sat all these years, you know, living on charity. And that's a dreadful thing to have to do.

IA: Taking you back again, the first paid staff that KCIL got, what was the role of the first paid staff?

AM: Oh, well the very first role of course was to do the secretarial work and answer the phone and those things, filing, all the sort of general secretarial work. And that didn't happen--, I was at the church, I think we had that office for four years, and I had a woman come in and help me voluntarily, she was very good, very loyal. But we couldn't pay her, I don't think we could even afford to pay her travel expenses in those days. It was awful, it really was begging for help. And I did four full days a week. You're saying did I-- , honestly, my memory, did I work with or as I in other groups? Yes, well the thing that was here was initially a group was set up for arthritis care, and I was asked if I'd be part of that, which I said yes. And that led on to me creating four new branches in the area. So there's one now in Cheam, there's Cheam for younger people. There's one in New Malden, there was a huge one in Kingston which seems to have dwindled quite a lot. There's was one in Thames Ditton I set up, and one in Epsom and Ewell. So yes, so I didn't attend the groups as an attendee, I actually took on the setting up and sort of management for a while till I-- , well, like any organisation, can you find someone to replace you. And the other group I've been involved in but hardly at all now because it's taken on a life of its own is something called YDAPAR, Young Disabled and Positively Artistic, so short YDAPAR. And that's for 11 to 25 year olds in the borough. And this was eventually headed up-- , Phil Levick, who's coming to work for us, he and I were-- , I went to the director, who was then Roy Taylor in the council, and said look I'm getting old, this was ten or 11 years ago now, I said look I'm getting old and I'm getting worried because there's nobody that is here who's younger, particularly a lot younger, who understands the history, the backcloth and all of that. So he said well look Ann, I can't give you any money but what I will do is I'll give you my office to meet in and I'll give you a senior social worker. So I got Phil, and Phil and I worked-- , oh it was a good year, with one or two other people that we pulled in, particularly like a children's worker, people who worked with children and understood them a bit more than I do. And then by good fortune there was a disabled artist in the borough who had an exhibition in the church, and I went up to her and I said look how would you fancy teaching young people. Oh she said, that's a job I'd absolutely adore. Little did I know it at the time but we got the most dedicated, committed person. And she worked tirelessly for ten years keeping that group going, she was so clever, she could involve any child irrespective of how disabled they were, and she could teach them art, music, everything. And if she couldn't she got in specialist workers. She knew how to apply for money, she got pretty-- , she never paid herself, she got her travel and other expenses but not actually any pay, but she did that for ten years and then last year, I think it was last year, or the year before that, she developed cancer and oh it was terribly tragic, and she was really quite young. So that was a terrible heartbreak because the organisation-- , I mean I'm the Chair still of the organisation but I don't really do anything for it because it does run itself and the teachers and everything have all pulled together. And her husband and family have kept going the fundraising for it as well. So I've left them to it, there's no point in me fiddling-- , you know, not fiddling, but I mean they look to me for answers for things but not to actually do any of the physical stuff, which is great, but oh Fran was absolutely fantastic. Nothing was too much bother for that woman. I mean she arranged all the transport for the youngsters, if they needed it of course. She put on shows, she put on art exhibitions, she put on musicals, plays, oh those children loved her, and rightly so. So yeah, those are the things I've been involved in, so kind of a variety of things. But you know, with young people it's a shame because in some ways I'm very good at understanding young people, I've got a lot of young people that I mix with around me and family and so on. But it's not the same really as running groups and all of that side, which I don't have the time or the energy for any more unfortunately. Yes, getting older, that's the one thing of all-- , I mean I don't think there's anything bad about getting older particularly, I think it's just the energy levels, I don't have them.

IA: Okay. The main big change from the Centre for Handicapped, and how did it evolve to become the Kingston Centre for Independent Living? How did the name change come about?

AM: Well what happened was that across the country the language was really changing. Disabled people wanted-- , because disabled people were frowned on so much in terms of we were sort of lazy layabouts who didn't do anything and were burdens, we really wanted to change the image of our lives. And of course the reason that we were desperate to get personal budgets was because then we could have much more control over life. And to show the difference, this friend of mine in the home that I'm so upset

about at the moment or worried about, is that she could be living like me. She comes from family which were fairly similar to my own in everything. But a lot of parents at that time always felt so guilty and the doctors made them feel guilty about having a disabled child. But unlike my father, who was determined that I was going to make something of myself if he could possibly have anything to do with it, whereas my mother was a real softy and sweet, you know, because she didn't have-- , my mother was a very clever woman but she just didn't go out to work, there was in those days no need to whereas today it's imperative usually. So in the last week her brother took her to see a different home because of this abuse, you know, he wanted her to get moved and she needed to go and have a look and see if she liked it and see whether the staff could manage her and all of that and support her. And oh she was so excited because yes they said they would have her, they'd gladly have her, that they could allocate her the type of room she needed and wanted. All was going well until yesterday when it transpired that the budget that the house had allocated, the moving of it from one home to another seemed to be such a process, it takes months and months and months. And of course the room had gone, in a week it had gone. And her brother wrote me this long email last night, really upset because he's trying-- , he lives in Holland, that's the other problem, and so he keeps trying to phone people here to get their answers and they keep saying oh no well it's not for us, we don't deal with that, oh no you've got the wrong office, everything's wrong. And they then said, which is my point about control, well she can't choose which home she goes to, we're going to decide that. See, so you know, we're the ones that have to look after her safety and all of that, when she's perfectly intellectually okay, she and her brother can do that, that's not a problem. It's the old iron rod is still there dictating what you can and can't do. I mean when you think a couple of weeks ago I took into the home a water bottle, an ordinary water bottle with a long straw, because she is half laying you know, she can't really sit up. And she has to drink an awful lot, and I said would you like to try and be a bit more independent, because she really can't do anything, and she said oh I'd love it. So I took this bottle with this straw in to see if she could use it. But I wasn't strong enough to clip the bottle onto the side of her bed, because she was in bed at this time. So I said to the sister when she came in, can you just help me put this-- , "What does she want that for? We give her drinks, what's she fussing about? She doesn't need that." So my friend said, "Yes I do, I want to be more independent." Completely dismissed. "Well it won't go on the wheelchair." I said, "Yes it will, I've got it on my wheelchair, it fits on hers." In the end, she was so desperate for me not to do anything that she said, "Well it's totally unprofessional, she can't have it." I said, "Excuse me, but 99.9 percent of the population drink out of water bottles." Which we do, don't we? We carry our water with us and drink out of the bottle. So, oh it's cruel, it's just cruel. Yes they do make her drinks, but when they decide, when they've got time to stick the juice in the water and all of this stuff. Don't even wash the cup out between coffee and juice or water, you know, it's just awful. Anyway, enough of that. But you see what I mean, the person that we knew, the direct payments which they were called at the beginning, would change our lives significantly for those people that wanted them. And that's what's happened. She could have had a home, she could perfectly well have had a flat or a house, and she could have had personal assistance. But she's so ingrained and institutionalised that her parents never let her think for herself, they finished every sentence. So she's stuck. So that's where we're at really.

IA: When the name changed to Kingston Centre for Independent Living, how did it affect the level of involvement of more disabled people?

AM: Well it didn't really, that was the thing, because you see it's really important to understand that disabled people are so used to welfare, they're so used to being looked after, they're so used to people speaking for them and people still patting them on the head occasionally, there's so many people in that position. So the word independent living, unless somebody explains it to them they really don't know what it means. So you can see that we're between a rock and a hard place really. To me it means a lot, and it's very important. But to most people, all they care about is that the Kingston Centre for Independent Living can help them. That's what they care about, and that's a good thing. But we don't have a lot more involvement. The problem is, you see, that people have got to the point where people who are say in their forties and fifties, the people that could run the board, say, we've got people in this borough, disabled people who could easily do it. But they've been so disenchanted with KCIL that they won't come anywhere near now, and I think that's quite selfish because to be honest, I mean I've got one very good friend and she

said well I only do national work, when I retire and I can't do so much I'll come back to local level. But that isn't good enough for me. She'll come if there's something big and something where there's a bit of kudos, but apart from that. And that sounds awful of me because she's been a long term friend of mine, but at the moment I am very upset because I've done so much to say look shall we meet up, can we have a coffee together, and she hasn't responded even. And I know that she's busy, because parliament is busy at this moment and always will be, but on the other hand friends are friends and--, but we'll see what happens. I know what's going to happen, I know how it will end, and I'll either have to give in or be very strong. So we'll see which way I feel when I get the call [laughs]. Yes, so the change has been difficult in terms of that involvement. We desperately need a disabled person in the chair who's politicised with a small 'P'. You know, the big important thing about that is that we just know the issues. And those people are not giving their time to KCIL, and that's what really upsets me. Mind you, to be fair, on the other hand to be really fair to them most of them are now in full time jobs. That's another big problem, so they're like me really, at the end of the day they're losing energy. So I can understand it, but I still feel that they could be more involved. And one or two are from the outside, one or two are--, they will help, you know, if I write to them or KCIL writes and says look can you help with this survey or can you give us some advice or will you look at some papers for us, certainly they'll do that. So that's good, you know, that's a great help. But we just sometimes need their presence, and more regularly, because they've got so much knowledge and they can also be fun, you know, and it's just a shame. I just feel sad about it really. But who am I to say, you know, we've all got our lives and we need to do what we can with our lives and we can make choices.

JK: Do you mind if I interject really quickly? Ann, you mentioned the direct payments and the role that KCIL play in that. Would you mind just explaining a little bit about the history of that and when it was first introduced, and sort of what the aims of that were?

AM: Yes, I mean it's a fascinating history. The date, if you want to actually put a year on it, was 1981. There were four people in a Leonard Cheshire home down in Hampshire. Actually that's when it started in this country, I'll go back in a minute, but this is where it started here in England. And they wanted out, they were absolutely fed up, they'd got--, just like my friend is now you know, nothing to do, nowhere to go, no one to really give them any input in their lives that they could respond to. And they got together and they decided they wanted to live in the community, and they felt that the money that the authorities were paying to keep them in this home could well keep them in the community. So they got together, it took them five years of perseverance to get from that point to moving into accessible bungalows, because they were all wheelchair users. Or flats, I can't remember which exactly. And that was headed up by a man called Paul Hunt, who has written a book which I think may be out of print. But he was the leader of all of that. And he then went on, the national press picked up the story, it went on and inspired other people. Well before that happened I was actually already out in the community because I moved back in 1973 or 1974, but that's never been recognised that I--, I mean it wasn't with direct payments of course, and even they didn't get direct payments, the money still had to be laundered through the organisation. But fine, it worked for them, we saw it work for them and you know we begin to think yeah it could work for us, why don't we escape from these places? But it started in a place called Berkeley in California, that was where it all first started in America with this organisation of disabled people, and they had the same sort of struggle to get started and move on. So we really took the idea from them, and that's how Paul and his friends got set up. After that I think people really, and particularly disabled people, knew what the issues were but they didn't have any opportunity to come together in a group, a national group. But at the time when Ken Livingstone came in, that was when the money was starting to come. It was a very good opportunity because it was being given to minority groups. You know, that was when gay and lesbian groups were given money, it was when black groups were given money, all those sorts of things, and women's groups and disabled people. And so because I was with KCIL there was a London organisation, I can't think what it was called for a minute because it's not called that any more, but it's called Disability Rights UK now but it was a London based organisation. And I used to go there a lot, we went to training meetings, we went to meetings to chew the cud and sort out the issues. And that was very inspiring because it gave me a wider base and then I could bring back to KCIL what I learned, which was absolutely fascinating. And so that's how it started, and mainly our focus--, the Centre for the Handicapped in Kingston focussed on access

issues, as many groups did because that was--, because until we could actually get out, until we could travel anywhere, you know, the money that we did get through benefits we couldn't spend it on anything because we couldn't actually get to the shops or do anything. Go on holiday. So that was the turning point. And what had happened at that time also, Park House opened. Now Park House is in the grounds of Sandringham and was Princess Diana's family home. And the family bequeathed it to Leonard Cheshire who wanted to make it into a hotel for disabled people. Quite forward thinking. But I'm not sure what it's like now, but how I know it is I went there for four days or five days on a training course. We took the hotel over, we being disabled people, took it over and although it was for disabled people it was purely a hotel for holiday activity, not training. We took it on and I had there four days of significant training which--, I mean to sit in a room with a person who I'd never met but when we started talking to each other realised that our backgrounds, although we lived in very different parts of the country, had been very similar. You see I'd never met anybody really like that who understood the issues and could even inspire me, even though I was in the field it still inspired me. And from that training we formed a group of trainers so we could get more and more experience. And then we were wanted by everybody, because at that time all the health and social care providers wanted to know what they should be doing for access issues. So I've travelled all over England, Wales, Ireland, Scotland training staff. Usually I was away for four nights a week in different hotels, I led the life of Riley. I mean they had to pay for very expensive hotels because they were the only ones that were reasonably accessible. So it was absolutely wonderful, until I thought oh I don't know, I don't like this hotel with this food like this, I started to get a bit fussy. But you know, to be called a guest when you'd always been this burden, it was an amazing kind of thing to get your head around really. You know, because if I had a holiday I either went to a nursing home or a sort of holiday place for disabled people, that was all there was. And the first home I went to got closed down it was so bad [laughs]. Oh it was dreadful, it was really dire, I can't tell you. Put you to bed at 4 o'clock on holiday? But that wasn't the only thing, there was lots of dreadful things happened. Anyway, so yes and then when I met up with this friend of mine who is now in parliament, Jane, we lived--, oh she came to me, very first of all I met her because she came to KCIL because she wanted to move from her parents' house into the community, and she knew I'd done it so she wanted to know how to do it. So in the end she finished up in a flat just across the road from me which she was able to purchase because of the awful situation where her husband had HIV which he got through contaminated blood--, no, not HIV, he was a haemophiliac and he got poisoned by the blood because the government wouldn't pay to have it tested. So of course he came in eventually for a fair bit of money which enabled them to buy the property. So that was really good, and anyway she comes from a wealthy background so money's not a problem particularly. So that was all good, and then in the end when she moved and got on the road to success, because I think she had two degrees and you know she had two brains really, she worked with me and said look come on Ann, why don't we do what these other people have done and get direct payments, she said, then we wouldn't have to rely on getting up at 9 o'clock or 10 o'clock in the morning and going to bed at 3 o'clock in the afternoon, we can be free and make our own choices. Well I was terrified because I'd never done anything like that before, and thinking of employing people, oh it was mind boggling. But we were determined then, I really got excited by the whole idea. Because I was relying on district nurses, there was no community care at the beginning, and they used to come at 6 o'clock or half past five in the morning to get me up and midnight at night, so I was absolutely--, and I was working, so I was absolutely shattered. So that wasn't good. So anyway, yeah, so we read this policy paper on direct payments and how it could work in Kingston and we went to the director, we made this appointment and we went, and at the time we didn't realise but she'd handed in her notice, she was going, and I think she saw this as her swan song, because she was a real goer, she was a real doer and she was very much on our side. You know, when I think that in those days, 1991 I think it was, there was a big convention in Vancouver and we went to her and said look we want to go, this is a meeting of the world and this is the first big convention on disability, what about paying for us to go. Because they were paying for all other staff to do all these fancy things at that time. So she said okay, so we had two weeks in Vancouver at the council's expense. So you see, you can sort of make things happen if you--, well it wasn't about knowing who, it was just about--, well it was knowing who might have the power to do something. So we had a wonderful time, and yeah came back very much more knowledgeable than when we set off. I mean I think all we had to do was write a report to the council on what we'd done, what we'd heard, so that was good. So direct payments came in, and at that time we had a kind of

coordinator in KCIL and we said we've got to have a management group for this, we can't do it all on our own now because we want to get as many people in as are interested because we don't want to be only two people that are just hugging it all to ourselves, you know, we want everyone to enjoy the same sort of rights. And we set up a management group, we managed that for years, and then well before our chief exec came in, our current one Lisa, the previous chief executive didn't want that so it all went--, you see so many things have gone that were good. Because I think direct payments have got really big now and I think people like John in the office and others who all support helping people need help not with individual situations particularly, because that's their role, but with the policy, the whole side that needs a lot of guidance. And the changes that have been made, I mean I went to the CQC, the Care Quality Commission a couple of weeks back and I was appalled. I mean this is a big national organisation and they're still using dreadful language like--, you know, we're still all cases. And you know, someone like me, I'm not a rambler so I can't do journeys. They used to call us, we're all going on pathways you see, we all have to have a pathway on which they can notch up how much help we get or not depending how rough or smooth the pathway is. So you know, we're not rambler, we're not cases, we're not tartan hard-backed or whatever. And this language is so important, as you will well know, as to how people are viewed. So you know, that's how it came into being. It was managed by this group, then that's gone and I think the staff really have quite a tough job because there's so many query issues, there's so many things that if we--, and we need, what we also need, which I still don't think we've got right yet, is we need liaison with the local authority and the health authority regularly, like quarterly, to thrash out each other's agendas, see where we're going to get to and what we need. So they're yet in the future perhaps, but we also very much need an access officer or somebody that can do access for us. And how things come full circle. Phil Levick, who's coming back to work for us, was our first worker. He was seconded by the local authority to help us set direct payments and this management group up, and now all these years later here he comes, he's now been pushed out by the social services, the adult social care, and so he's coming to work for us. So it's terribly, terribly good and it's all very positive. And I think KCIL now is in the best place it's ever been. Just if only we could get a stronger board, we do need a stronger board, that's the only thing I think. Once we get a stronger board we would I think know how to do things a bit differently that would encourage the staff particularly, because I think we will have a good workforce. I mean I think the team's great now to what it was, great. But you know, you need to support people to keep them and have the money to do so. But also we need to encourage more disabled people to join us in the middle. You know, they like coming to things like--, they won't mind coming to the AGM because they get a free meal, well which everybody likes, you know, it's not unusual is it. But it is not good enough, and I tell them that, I've told them at several AGMs going now that it's not good enough to just keep saying yes we like KCIL but then don't support us enough. What's the next question?

IA: In terms of paying for your care and all that, can you tell me a little bit about the means tested charging policies?

AM: Oh don't, don't start me on means testing. Because the policy over the years has changed from--, how they used to do it, rather than dig into everything they used to look at people who had Disability Living Allowance and they would look at what expenses they had and then they would take a portion of that. I mean it varied between people, but they decided how much was fair enough, you know. So that's how it worked to start with. There were a group of us that knew things would change, I mean you can always see how they're going to change, can't you, really. And so we stuck together, there was a little group of us, so we paid all our--, we used to pay everything like we were told to pay. But we stuck together just so we could find out what was going on really underneath by the council. Then they decided that they were going to charge people 50 percent of their disposable income, and they managed to get that through. They then went on, oh was it three years ago now, two years ago? Anyway, they went on to ask for 75 percent of people's disposable income, and that was after they'd sort of thought about disability related expenses. But they didn't have a definitive list, it was all done just by guesswork really. Anyway, that was passed, and that was terrible, that was an awful meeting when that was passed, people were crying and sobbing you know, they said we can't afford any more. But the council decided that they could. And then last year was the big struggle when they then said they were going to put it up to 100 percent. And we did all we could

to get them to change their mind. We went to council meetings and people made speeches and all of that, but the council said no we're going to charge 100 percent. So that's where we're at with it. And it's very difficult because alongside that the finance department have been in such a muddle, they've made some horrific mistakes. And I say that advisedly. And a lot of the things that are happening which they know about, or at least they've been told, is that people have got quite large sums of money in their accounts that they've not been able to use. And when we had the meetings to do with the 100 percent, because I have a lot of money in my account, when I learned that other people had got even more than me, some of them, I was really shocked. Because it was serious. For example, so when I knew that they'd made so many mistakes that I'd accrued this money just through their mistakes, I wrote to them and said look this is your money, here's the cheque, I'm giving it back to you so you know that's your money. And guess what, unbelievable, ten days later I got a letter saying thank you for sending the cheque but we're sending it back to you, we don't want it, you can spend it how you like. I'm not talking about £100, I'm talking about thousands of pounds. So of course that made me very nervous, I didn't like that at all. So I almost immediately went to the bank and took out all this excess and put it in a separate account, because I thought well it's so transparent, they cannot say that I spent a penny if anyone challenged me. Because it was really scary stuff you know. Because down the road, two miles down the road another friend of mine, more or less at a similar time to all this going on for me, she was sent an invoice for £24,000 they said she owed. See what a mess they are in? Well, she had a breakdown over it, it was terrible. And she sent a letter saying give me a breakdown, and they just sent a letter saying this is what you owe, nothing to say how she owed it. And so they then said they'd re-examine it, and so they brought it down, I think it's now £22,000. But they haven't told her how they've deducted the £2,000 and they haven't told her how they've made the £22,000. So she's still in this position and they have not moved. And then when I--, I've now got a social worker allocated because of my review, and I said to her you do know don't you that I've got this money, I said I have spent a lot of it, or quite a lot because I said I was ill last year and I had to have people sleeping nights so I've had to pay them. And I didn't have the money in my budget to pay. So she said no that was fair enough. Anyway, she went down to KCIL to examine all my accounts and has come back saying there's nothing much wrong with your account she said, the only problem is that you haven't got enough to pay your--, from now on there is not enough money in your account to pay your staff. I said I know that. But I said that's why I put this other money into another account and then I can demonstrate, when I have to move it to pay, how I'm using it. Because that's all I'm using it for, I'm not gallivanting across the world with it, you know. Anyway, she's coming tomorrow. When she came the last time I said well--, no, the time before, because it's her third visit now, I said to her oh I said well you've been so polite to me and you have been understanding of the situation so as I respect you I'm willing to give you some of that money back now, despite the fact I haven't got enough myself, but you know I could keep some and give some of it back. Oh she said, well we have been talking about it in the office, I said well I expect you've been talking about me and saying how awful it is that I've got all this money. No, no, she said, we hadn't been doing that but we have been talking about how this has happened. I said well I can tell you how it's happened, there's no difficulty with that. Anyway, she said when I come next time we'll sort out how much you'll give back. When she came the next time I said well at the moment I've decided not to give any of it back, I'm so angry still over the whole thing that if I give it back to you it'll seem as though the issue is closed and it isn't, it's still ongoing, it's still a worry to other people. I said until that finance department gets its act together I can't trust them, I said it could go into mending holes in the road. Which we desperately need mind you, but I said I can't trust them to put it in the right account. I said if I thought that was going to fund another care package or two I'd give it to you today, but I can't trust them. So that's where I stand. But it's so uncomfortable, it's horrible you know, it's brought me down to the level of thinking you know, shall I top myself. I said to her, you know, it's all very well but these things aren't taken lightly, you can't just say oh well it's the council's fault, you've got to think where you are in these dreadful situations. But I know other disabled people are--, and at least what's happening is that it's not so much disabled people, it's the parents of disabled people who know that they're sitting on this money. But we've tried to give it back and tell them but they're not listening, just like they didn't to me. So that's where we're at with charging and means testing, it's awful. I don't know what the time is.

IA: So with all that's going on, how do you see the future support for people living with disability?

AM: How do I see the future? Well, in some ways I see it in a more hopeful way because the policy now is that people should be entitled to remain at home if they want to with direct payments. And for those people that don't then you know you must respect it if they've had choice. The trouble is that often people don't, they either get put into a home for example if they've had a crisis and they're not deemed fit enough or their relatives don't want them on their own because they can't tolerate the idea of them having a fall or whatever. So it's all tricky so you have to look at it from all sides really. But the future is hopeful, I think younger people are not going to tolerate being put into homes any more, and anyway the homes aren't there for younger people particularly. I think for people who are self funding, totally self funding, I think there are issues there. The council promised people, or at least the law said that people would be promised support and help, but the council want to charge them an awful lot of money for that. But also a lot of people rub along with a neighbour still and just give them a pot plant or a box of chocolates, or they do pay people who they know are hard up to come and do their shopping and laundry and all these things. But it's not a good system because at some time those people leave and then they've got no one to fall back on and they could have big gaps in their care. And the council I don't think have no knowledge of who are self funders, so they're not keeping an eye on people in terms of ensuring their wellbeing. That's as far as I know, I could be wrong but I'm sure that is right. But I do see it as more hopeful because I think the younger older people won't want to go into homes, they will want to stay in their own home usually. Occasionally no, I had a friend that made a positive choice to move into a home, but then she'd got no relatives whatsoever, no one to look after her, and she knew the home intimately because she'd visited it for years so she knew what she was going to get, you know, what she could tolerate and what she couldn't and so on. So people have got that choice if they've got the money. If they haven't then it's very different.

IA: And how do you see KCIL evolving in the future?

AM: Right, well I think we've moved quite a long way in the last five years considering how long we've been around. Because I think we've got far more dedicated staff. I mean I know people have to leave and so on, but that's in any employment today. But the people we've got you know are good and we make sure we try and keep them. But what we've got to do if we're really going to change I think in any significant way, is I think we've got to get a board that really understands the issues, and I mean really understands them. They understand equality, they understand people's rights, and I mean that in a way--, I don't mean where you sit on the street and shout, I mean just saying yeah well I know this is my right and this is what I'm entitled to. So we need to, you know, think about how we're going to give disabled people more education around sort of the politics of it all. But the trouble is we've got a group that will meet around direct payments or personal budgets, but often they're very poorly attended. I think they've got a little bit better. So we've got to really major on all that side of it and try and I think bring people together to oversee the issues. And I hope we can do that, I do feel that we've got to make a big effort but I think we can do it. And we could educate people I think, or train people I think, because they don't--, you know, it doesn't matter that they don't understand the issues, I think once they come together and people start talking then they begin to put it into that political scenario. But when people don't know how systems work, that's very difficult. And even those that are in the systems don't know how they work, so that's another problem [laughs].

IA: So looking back, is there anything you think you could have done differently?

AM: What, on a personal level or on a KCIL level?

IA: Both.

AM: I truly believe that from a personal viewpoint I don't think I could have done more than I've done. I've had a very good life, and still have a good life. You know, I've had lots of opportunities and I feel I've taken risks in a meaningful way that have given me a good life. And although things that I had done in the past, like on a health level, would never happen today, I still think even that--, looking back although it was

terrible and the places I was in were awful, I survived them, much to people's annoyance, but also I think some of the doctors whose knowledge at the time I was born was very limited, they still did the best they could and in fact those things have worked out better I think than if I had had modern medicine today. I don't know, who can tell, you can't, it's subjective. But it's a thought. And yes, so no I've had a brilliant life, I've been all over the world, I've done so many--, I've met so many great people, I've done jobs that have been really difficult but I've still managed to struggle through them. So yes, so that's on a personal level. KCIL level? Could we have done more? Could we do more? I don't think we could, apart from--, and even saying this, I think if we could have moved a bit faster in some areas it might have been better. But unfortunately in the field that we're working in I think you can only go as fast as people can go, and rather than upset everybody and finish up with nothing we have to move intelligently and try and work with people that don't know, and let them think they do [laughs]. Just so that we can get what we need if we can at the end of the day. Yeah, so, any last thing that you want to ask?

IA: What would you say is your most proud achievement?

AM: Well until a few days ago I don't think I could have answered that. But it was--, I'd completely forgotten, but on Monday when I went to this celebration of Wycliffe Noble's life, who started KCIL, his wife kept going round introducing me to all these people I'd never seen before in my life and saying, "Now this is Ann, she's terribly important to us because she got Wycliffe the OBE," and for that kind of class of person the OBE was terribly important. But I'd forgotten, that was so many years ago now, and amongst all the other things that have come since, but she was so thrilled that he was so recognised in the end as well. Which he should have been, he deserved any accolade he got.

IA: And how did you yourself feel about being recognised for the OBE and the MBE?

AM: Well, the MBE not so much because what happened was I was working that day, I couldn't get out of it, I was training. And I rushed to the palace, I had to change, rush back out and get into other clothes and then go back to work. So it all went by in a bit of a haze really I think. And it was a freezing cold day and you don't even get a cup of tea there, you know, on those days. When I got the OBE it was really lovely because my family were able to come. I wasn't--, you know, I had the opportunity to sort the date out properly so that I could get there calmly and all the rest of it. And I think it was nice for my family. My parents weren't alive, sadly. My father was alive when I got the MBE but he was too ill to come, so I think... yeah I think they would be proud anyway, and that was the pleasing thing. Because you know, from somebody who they thought would never work, well the doctors told them I wouldn't even hold a pencil, so you know, that was tough for parents in those days, so they would be pleased. I'm sure they're somewhere around and know it all.

IA: Okay. Is there any other thing you'd like to share that I haven't asked?

AM: I think you've done a thorough job, I think, of getting it out of me and me telling you.

KC: Okay, on that note we can stop the recording

AM: Yeah, well thank you so much.

IA: Thank you very much.

[END OF RECORDING – 01:40:25]